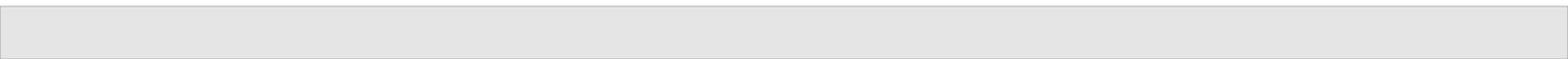




Who Owns Patient Data Under “A Better Way” Healthcare Reform

An ESI Healthcare Business Solutions Position Paper
by Leo Lopez, CEO



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With the presidential election now over, it's with great certainty that ACA health reform will take a new direction. Speaker Paul Ryan's Task Force Plan on Health Reform unites proposed changes under one vision and is the answer to the failure of ACA by articulating a new way of reform – A Better Way – A Vision for a Better America. Anxiety and uncertainty will begin percolating through the staking of positions of preference by the various stakeholders. The sunken costs to-date of implementing the ACA are so large that business stakeholders will provide a leadership role to assure that their sunken investments and potential new ones have a sustainable ROI.

The guiding principles of ACA including affordability, quality, availability and cost reduction are similar to the stated position of Ryan's Task Force of accessible, affordable quality care. The main difference will be in the implementation of a reform package that eventually eliminates the failed and convoluted rules and regulations of ACA. However, a first glance of the proposed reform, a significant difference will be the emphasis on recognizing that **people** will come first by empowering the patient through the support of data driven **innovation**. One thing certain is that the patients, providers and their corresponding business associates will be evaluating which business models work best under reform and have a sustainable rate-of-return (ROR) with minimal risk.

Aside from the turmoil of reform, there is one common element that is integral to the success of the reform models; **unburdened access to patient data is a non-negotiable starting point for A Better Way to succeed**. The question of who owns patient encounter data must be answered in moving forward with developing and offering new and innovative products and services. Perhaps patient data should be viewed not in terms of ownership, but as a “national resource” that is made available in an unobstructed manner to the patients, providers and their business associates. Of course all legitimate users of patient data must comply with minimal federal and state rules and regulations to assure the privacy and protection of data. A more workable solution is to treat **all entities** including providers, their business associates, all data sources and other service providers as temporary “stewards” of patient encounter data.

At present there are too many entities that claim ownership of patient data including, providers, billing services, pharmacies, information exchanges, patient registries, clearinghouses, Pharmacy Benefits Managers (PBMs), data aggregators, Electronic Medical Records (EMRs), federal and state agencies, insurance companies, and payors. Separately these entities structure barriers including Data Use Rights as a means to deny the much needed access to patient data. If the patient/provider will be at the center of reform, consent by the patient should drive all further access and use of this data. It is expected that any business associate aggregator of data who adds value through analytics should pay a reasonable fee to access such data. Therefore, not having access to patient data is the main concern and crippling issue, and **NOT** the payment for the use of such data.

Example of the data ownership dysfunction:

For illustration purposes, consider some current examples of how restricting access to patient medication history data is problematic for business associates in developing value-add services for providers.

When a provider prescribes a medication for a patient, the proper patient consents have been secured by the provider, and the request is submitted to a pharmacy or PBM for fulfillment. At this stage the pharmacies and PBMs claim ownership of the data and dictate how this data may be used or disclosed by them without pre-authorization or opt-out of the patient. The pharmacies and PBMs submit prescription medication data to a clearinghouse for adjudication and claims processing to payors. The clearinghouse is allowed to resell certain data to certain provider business associates, but only in an acute care setting. Why this medication data can only be used in an acute care setting defies logic. What happens now to the legitimate need for this data for post-acute care? In order for the clearinghouse to entertain requests from business associates to use the medication data in non-acute care settings requires granting user rights from thousands of pharmacies and multiple PBMs. This obstacle disregards the original consent the patient has already given for the use of his information for downstream purposes.

A second example of problems in making patient data available to develop and provide innovative services is the PBM market. A company secured enrollee consent and requested to purchase pharmacy data from certain PBMs for use in much needed analytics in health insurance underwriting. The company was denied access to purchase data by some of the PBMs because they staked all ownership rights to PBM patient data and did not want competitors in the health insurance underwriting marketplace.

In conclusion, patient encounter data is a “national resource”, and the patient through minimal federal and state rules and regulations should be the one to consent (or not) to sharing of his data downstream with all who have a legitimate and contractual agreement to provider services. A reasonable fee must be paid for use of this data and accomplished without obstacles by third-parties in order to successfully implement health reform.